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ABSTRACT

Two surveys, one qualitative and one quantitative, were conducted of the opinions and experiences of New York State parents of children with learning delays and disabilities regarding parental labor force participation, child care options, and preferences in state policies. A total of 141 parents responded to the quantitative survey and 210 to the qualitative survey. Twenty-six key findings are reported. Strikingly convergent results were found from the two surveys, including a lower participation rate by mothers of children with disabilities in the labor force than by mothers in general, and a common desire for special services to be provided at regular child care and early childhood settings. Most parents, particularly mothers, had made major sacrifices, adjustments, and compromises for their children but differed in the degree to which they believed public policy should consider their needs as well as those of their children. (DB)

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"MY LIFE WAS TURNED UPSIDE DOWN . . ." CHILD CARE AND EMPLOYMENT AMONG MOTHERS OF YOUNG CHILDREN WITH DISABILITIES

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This Working Paper has been adapted from the Final Report of a study conducted by the Wellesley College Center for Research on Women and the New York State Child Care Coordinating Council (NYSCCCC), with federal funds provided by the New York State Developmental Disabilities Planning Council (DDPC). The study was co-directed by Dale Borman Fink of the Center and Sandra Lamm of the NYSCCCC.

The title of this Working Paper, "My Life Was Turned Upside Down," is excerpted from one of the surveys received in the study.

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"MY LIFE WAS TURNED UPSIDE DOWN..."

CHILD CARE AND EMPLOYMENT AMONG MOTHERS

OF YOUNG CHILDREN WITH DISABILITIES

What arrangements are preferred by families of children under six with developmental delays and disabilities for the care and education of their children? What proportion of their children receive care and education in specialized settings designed exclusively for children with delays and disabilities, and what proportion attend generic settings, i.e. nursery schools, preschools, and day care homes and centers that other children also attend? Are the current arrangements determined by personal preference, by state and local policies, or by some other factors?

Do mothers of children with developmental delays and disabilities seek to join the labor force? If they do, how are they affected by current child care options and state policies? What state policies do parents favor?

In order to help the state of New York answer these and other related questions, the opinions and experiences of parents of children with learning delays and disabilities were assessed by means of two surveys--one qualitative and one quantitative.

QUALITATIVE INFORMATION-GATHERING

Through a variety of information channels, parents or guardians of children under six with developmental delays or disabilities throughout the state of New York were invited to fill out questionnaires. In addition we looked for responses from key informants--those who had contact with families of children with special needs and could provide helpful insights.

The study team received 210 completed parent surveys from 35 counties throughout New York state. There was a somewhat disproportionate number of parents from rural areas, with suburban and urban fairly evenly represented. The respondents represented a good cross section of low, middle and high income households. In analyzing the information gathered from these parents we searched for repeated themes, common practices or experiences, and widely shared assumptions or opinions.

QUANTITATIVE INFORMATION-GATHERING

The objective of our quantitative information-gathering among parents was to draw a statistically reliable portrait of current arrangements and opinions that would draw from geographically and demographically diverse areas of New York and represent something

more than a self-selected group of highly motivated respondents. To accomplish this aim, the study attempted to draw representative samples of parents of children under six with identified delays and disabilities in four places and survey those samples through the mail. The following geographical areas were chosen:

UPSTATE URBAN AREA	City of Albany
DOWNSTATE URBAN AREA	Brooklyn
RURAL AREA	All of Essex and Franklin Counties
SUBURBAN AREA	Dutchess County excluding urban and rural areas

The tasks of identifying and gaining access to a representative sample of parents in our targeted areas were carried out somewhat differently from one area to another. But in all cases, survey respondents received along with the survey a cover letter on the letterhead of a local agency with which they had an ongoing relationship. This letter explained the purpose of the study and also assured respondents that their confidentiality had been preserved.

How Representative was the Population Surveyed?

In all targeted areas except Brooklyn, we succeeded in accessing a fully representative sample of families, including those whose children received home-based services, those whose children attended a variety of special educational settings including therapeutic preschools and nurseries, rehabilitation centers, etc., and those whose children were among the "special needs" enrollees of Head Start. In Brooklyn, we started out working with two agencies which had the potential to access similarly representative samples; however, low rates of return (less than 2%) caused us to toss out these results and redo the survey, working with a third agency. We selected this agency because all of its clients received home-based services. While this gave us a less representative sample, the agency's strong relationship with its home-based clientele succeeded, as we hoped it would, in producing a rate of return comparable to or better than that in other areas of the state.

Quantitative Survey Results

TABLE A illustrates the number of surveys mailed out and the percentages (and numbers) completed and returned, by area. A total of 468 families received the surveys in the four targeted areas. The rate of return, taking the four areas together, was 30%. The rates of return varied from 15% (Albany) to 48.5% (Dutchess County).

TABLE A Responses to parent/guardian survey on care arrangements of children with learning delays and disabilities

AREA	PERCENTAGE OF PARENTS/GUARDIANS RESPONDING (N)
UPSTATE URBAN	15% (22)
DOWNSTATE URBAN	32% (36)
RURAL	31% (31)
SUBURBAN	48.5% (52)
TOTAL	30% (141)

NEARLY ALL RESPONDENTS MOTHERS

We found that 93% of the respondents to our quantitative survey identified themselves as the mother of the child in question. Thus, when we speak of survey respondents in the discussion that follows, we are for all practical purposes speaking of mothers of young children with special needs.

HIGHLY REPRESENTATIVE SAMPLE

Our sample of completed parent/guardian surveys was in many important respects a very good representative sample of families of children under six with developmental delays or disabilities.

Urban/Suburban/Rural

By urban/suburban/rural, the sample divided as follows: 41% urban; 37% suburban; 22% rural.

Ages of Children

Our sample included 2% children less than one year old, 16% one year old, 22% two years old, 26% three years old, 22% four years old, and 12% five years old. Grouped together, we find that 40% of the sample was less than three years old, with 60% three and up. The downstate urban sample was mostly (81%) under three years old. The upstate urban sample was almost entirely (90%) three years old and up.

Number of Disabilities

By number of disabilities, 46% of families identified one disability in their child; 28% identified two disabilities; 11% identified three disabilities; and the remaining 15% identified four or more disabilities.

Individual Educational Plan

At least 63% of the entire sample (82% of respondents who answered this question) were sure that their children had an IEP. (Some others were "in process" or "not sure.") Our positioning of the question may have missed respondents whose IEPs called for home-based services, as it was placed among the questions posed to those whose children attended out-of-home programs.

Severity Level

By severity level, nearly equal proportions of parents reported their children to have only mild delays or disabilities (32%), to have a moderate delay or disability in at least one area (37%), and to have a severe disability in at least one area (30%).

Types of Disabilities

By types of disabilities reported for their children, the sample fairly reflected the distribution of disabilities found in the special educational population. "Speech-delayed" or "speech-impaired" is the label most commonly given to young children with developmental problems of a wide variety. Reflecting this, 72% of our sample marked speech as an area in which their child had a delay or disability. Next largest was physical disability, which was checked off by 27% of our sample, followed by learning disability, which was selected by 22% of the sample. There were smaller but significant numbers who selected hearing impairment (13.5%), medical fragility (13.5%), mental retardation (11%), other health impairment (11%), and visual impairment (10%). Another 6.4% marked autism and 5% checked off mental illness/emotional disability. There were also 11% of respondents who wrote in cerebral palsy; however, we believe that undercounts the number in our sample with cerebral palsy. We did not include it on the pre-printed list of disabilities because we wanted families to identify their children's disabilities by specific functional areas. Small numbers of families wrote in attention deficit disorder (3%) and developmental delay (6%).

There were few significant differences among types of disabilities across geographical areas. However, none of the rural parents (0%) reported having a child with autism and significantly fewer of them had children with physical disabilities (10% as contrasted to other areas with a range of 18% to 42%). The rural respondents also had fewer children with severe levels of disability. The label learning disability was much more likely to be reported by respondents in the suburban area (42% as contrasted to a range of 11% to 23%). Brooklyn respondents were the least likely to report that their children had speech impairment (53% as contrasted to other areas with a range of 67% to 90%).

Income Level

By income level, our sample was evenly divided from low to middle to high incomes, with 21% reporting gross annual household income under $10,000; 27% from $10,000 to $25,000; 28% from $25,000 to $50,000; and 25% above $50,000. Also, we found 13% of our sample receiving Aid to Families with Dependent Children (AFDC). The rural area contained the highest proportion of low-income families in our sample. The rural area and the upstate urban area contained more respondents receiving various forms of public assistance than the suburban sample or the downstate urban sample. The upstate urban sample had mostly very low income (under $10,000) and very high income (above $50,000) respondents, with fewer in the middle ranges.

Number of Children in Family

We found that 21% of the sample had only one child; 37% had two children in the household; and 42% of the sample had three or more children in the household. The number of families with three or more children in the household was significantly greater in the rural area and in the downstate urban area than in either the suburban area or the upstate urban area. Also, 14% of our sample had at least two children under age six with disabilities.

Racial Minorities, Single Parents Under-represented

Survey respondents did not fully reflect the proportion of racial minorities and single parents with children with special needs. Our survey respondents reported themselves as 90% white, only 5% black and 5% other. Our respondents consisted of 80% two parent households, just 20% single parent households. However, it should be noted that this under-representation was not built in to the "universe" that we sampled; rather, these results reflect lower rates of return among racial minorities and single parents.

KEY FINDINGS

In the observations and discussion that follow, statistical findings are drawn from the quantitative parent survey and direct quotations are drawn from the qualitative parent survey. These findings are further embellished by information gained through interviews with parents and key informants.

1. In choosing care arrangements for their children with special needs, twice as many respondents felt that they had enough options as felt there was a lack of options.

When asked about choosing their current arrangements, 44% of respondents selected had enough alternatives, 22% selected forced to take whatever could find, and 34% selected somewhere in between. Many respondents wrote in comments, often to clarify that their level of satisfaction with their children's programs was not directly related to the availability of alternatives. Typical was one who had marked forced to take whatever could find but wrote in "very happy with program!"

A Cortland County parent of a child who attended a rehabilitation center seemed to speak for many others in writing, "I was satisfied because they were very good to our son. I was dissatisfied because it was the only place to take our son."

2. Just one out of six respondents reported that a child care or educational program had ever refused to enroll their child on account of disabilities. However, nearly half of respondents identified some kinds of problems in finding care for their children.

Just 16% of respondents answered yes to the question, "Has any child care or educational program ever refused to accept your child on account of disabilities, or asked you to withdraw your child on account of disabilities?" There were 84% who answered no. Our suburban sample was much more likely to report they had ever been refused care (25%) as contrasted to the other areas (6% to 16%).

When asked to check off a list of possible problems in finding care, just 36% of the total quantitative sample checked off none, while 46% marked off at least one problem out of a list of ten. Lack of information about options available and care too expensive were the problems noted by the largest number (27% each). Next most common was limited or inconvenient hours (20%), followed by getting specialized services coordinated with care (18%), and inconvenient location and lack of qualified caregiver (16% each).

3. Most respondents had not looked for care or education in generic settings. Those who had were less likely to report that they "had enough alternatives" and much more likely to report that their children had been refused on account of disabilities or that they had problems finding the arrangements they wanted.

When asked, "within the past 12 months, have you ever looked for daily care or education for your child (outside your home) in any setting which was not a respite care, special education or early intervention program?" only 27% of respondents answered yes. The remaining 73% answered no. Respondents that had other children in the household besides the one with the developmental delay or disability were less likely (24% to 26%) to have ever looked for care in a generic setting than those with just one child (39%).

Of the 27% that had looked for generic care settings, just 25% indicated that they had enough alternatives. There were 31% who felt forced to take whatever could find. Also, 31% had had their children refused or been asked to withdraw their children from care and 86% had experienced problems finding the care they wanted.

4. When respondents' children had been refused care, the main reasons that had been given--pertaining to the children's functioning--were communication skills, behavior problems, and toileting skills. Additional reasons given--pertaining to the care setting--were lack of experience, lack of staff and lack of staff training.

We asked, "If you have ever been refused child care...or if your child has ever been asked to leave a child care program, what reasons were given?" Of the reasons that focussed on the child's functioning, difficulties communicating with others was selected by 35% of those who had encountered this problem, followed by behavior problems and toilet training issues (30% each). The other main reasons given to respondents by providers spoke to the inadequacy of the caregiving environment: lack of prior experience with special needs (44%), inadequate staff training (35%), and not enough staff (26%).

The mother of a one year old born 12 weeks premature in Niagara County explained that at age 10 months, her son was refused by a provider "because of medical problems and delays, who said we needed a nurse--untrue!"

5. As incomes increased, respondents were more likely to report having looked for care in generic settings.

Just 16% of respondents with annual incomes under $10,000 had looked for care in non-specialized settings. That proportion rose to 26% for those with incomes from $10,000 to $50,000 and to 34% for those with annual household incomes over $50,000.

6. The numbers of respondents whose children were enrolled in segregated special education or early intervention programs were vastly greater than the numbers attending any other types of educational or child care settings. Care in someone else's home was the next most frequent arrangement.

We found that 63% of our respondents answered the section of the questionnaire designed for those who "USE CARE AT A CENTER OR SCHOOL." Because our Brooklyn sample was taken from an agency providing home-based services, only 29% of those respondents answered this section. In the other areas, which were more representative of the population as a whole, the use of center-based or school-based programs was much higher: rural area (47%); suburban area (87%) and upstate urban area (86%).

Of respondents whose children attended center-based or school-based programs, the greatest number by far were special educational settings. Of the respondents whose children attended programs, 84% indicated that the program the child attended for the most number of hours was a special education/early intervention program. Another 10% indicated Head Start, with small numbers attending day care centers, public schools, and nursery schools for the most number of hours.

We found that 23% of the respondents (including some of the same ones that used programs) answered the section of the questionnaire designed for those who "USE CARE IN SOMEONE ELSE'S HOME.

A parent from Orchard Park (Erie County, suburban area) wrote that her two year old with left side hemiparesis, a seizure disorder, speech delay and motor function delays "was taken out of day care and enrolled in UCPA program to give him the best opportunity available to him. I can't imagine what my son would be like without the UCPA program."

Similarly, a parent from Bedford-Stuyvesant whose daughter is blind said, "You're not going to let your child go anywhere besides the Lighthouse [a program for children who are blind or visually impaired] if she's blind, are you? When I finally did want someone else to look after her, the baby sitter I found was someone who had worked at the Lighthouse and who knew a lot about blind children."

A mother of a one year old with cerebral palsy from Depew (Erie County) wrote, "the people in your everyday day care centers do not have the necessary skills and training to watch a disabled child such as ours. Would you leave your disabled son or daughter to just anyone at a day care center? I don't think so."

A parent of a one-year old with Trisomy-18 from a rural community in Erie County told us that, "They didn't expect her to survive after she was born, but now that she's past one year, I am starting to think of what kind of situation would be OK for her. Maybe a home care situation where I could trust the other parents."

7. Respondents whose children attended integrated programs were much less likely to report they "had enough alternatives" and reported many more problems in finding care arrangements than those whose children attended segregated programs.

Of those whose children currently attended an integrated program, 25% said they had enough alternatives, compared to 47% of those whose children were in segregated programs. Also, 77% of those whose children were in integrated programs reported that they had problems finding care arrangements, compared to 51% of those whose children currently attended a segregated special education program. While only 15% of those currently in segregated programs had ever been refused care on account of disabilities, the same was true of 37% of those currently attending integrated programs.

Location showed up as a significant difference: 41% of respondents whose children attended integrated programs identified inconvenient location as a problem they had encountered; it was only a problem for 12% of the other group. (It would appear that the provision of free transportation for children attending special but not generic programs would account for the difference in response on this point.) Not surprisingly, getting specialized services coordinated with care was more often a problem for those using integrated programs (29%) as opposed to those using segregated programs (15%).

8. Respondents whose children had only mild or moderate disabilities were three times as likely as those whose children had severe disabilities to use integrated programs.

We found that just 10% of respondents who identified a severe level of disability in at least one area reported their children attended center-based or school-based programs that also enrolled children without special needs. By contrast, 31% of each of the other two groups--those with mild or moderate levels of disability--indicated that children without special needs attended such programs along with them.

9. The main reason that respondents reported for using any types of care and education outside their homes was the child's developmental needs, not parental employment.

In response to the question, "What is the main reason your child has attended child care or an educational program outside your home?" 92% of our quantitative sample checked "child's growth and development." Just 8% checked "parent employed."

A teen-aged parent from Brooklyn told us that her four year old, who gets picked up by a bus each morning and taken to the United Cerebral Palsy Association program, would be home with her if the child had no disabilities. The parent is living with her mother and her other daughter, a one year old.

A parent living in a rural community in Jefferson County reported that her two year old son attends a rehabilitation center because of his need for physical therapy and his profound hearing loss. Her hope is that intensive work with her son will allow him to have an integrated placement by the time he is of the age for public school entry.

10. Most respondents (93% of whom were mothers) were not employed outside the home.

Just 35% of the respondents in our sample were employed outside the home, while 65% were not. This contrasts markedly with national estimates that 54% of mothers of children under six were in the labor force as of 1988 (Lubeck and Garrett, Social Policy, spring 1988).

11. Respondents whose children had a severe level of disability were significantly more likely to report that lack of child care had kept them from being employed.

To the question, "Have problems with finding child care for your child(ren) with disabilities kept you from being employed?" we found that 18% of respondents whose children had mild disabilities answered yes; 19% of respondents whose children had moderate disabilities answered yes; and 31% of those whose children had severe disabilities answered yes.

A Cortland County mother of a child with multiple disabilities and medical involvement wrote, "I was just thinking of going back to work when our son got ill. After that my life was turned upside down. I didn't think I would ever leave the house again, let alone go to work! Now I do get out, thanks to respite. But it's still not enough to let me go to work."

A parent of a three year old, nonambulatory child with cerebral palsy wrote that she hasn't had to quit a job yet, but "it is getting harder and harder to work full time, take care of a house and the children and find a sitter that is not afraid of A., that they might hurt her or that they don't have proper training."

A mother of a three year old with cerebral palsy and visual impairment from Mayfield (Fulton County), wrote, "I was offered several job offers the past three years and I have declined because of remarks by outside caregivers, such as, "she's still in diapers?" "we don't allow children to sit so close to the TV," etc.

A mother of a five year old with a rare chromosomal abnormality and multiple disabilities from Schenectady County wrote that, "I had such a bad experience with child care that I stayed out of work for two years before getting up the courage to try again...my son was virtually ignored; his 3 year old sister took care of him at the sitter's. None of this came out until my daughter realized we were moving and she wouldn't ever have to go back there again."

12. Half of all respondents reported that they or another adult in their household had experienced job-related problems in connection with their child care arrangements in the past year.

Given a list of 7 job-related items and asked to check whether "your household has experienced any of the following difficulties in the last 12 months due to problems with child care arrangements for your child(ren) with disabilities," 50% of respondents answered yes to at least one of the items. The most extreme effects were registered by 16% who had to quit a

job and 8% who did not accept a promotion. More common were milder effects: experienced more stress (47%), had to leave work early (50%), and late for work (42%). Another 11% returned to work later than planned after birth of baby or adoption of child.

There were no significant differences in job-related impact by income level of the respondents. Respondents from our suburban and upstate urban samples were somewhat more likely to report job-related impact than our rural and downstate urban samples. Of respondents who were currently employed, 77% reported job-related difficulties experienced by someone in the household. Of respondents not employed, it was 37%.
Melanie Conners, Head Start Director for the St. Regis Mohawk Tribal Government, stated that "the mothers I know of whose kids have had special needs had night jobs or weekend jobs."

A mother of a two year old with cerebral palsy from Erie County wrote, "My husband gave up his job to assist in caring for our son. He has found a new job recently and arrangements between us have been made to achieve the needs of our son at UCPA."

A parent of a speech-delayed four year old wrote that, "I had to switch my hours in order to provide care in early intervention. It still poses problems on days on which there is no school."

13. Center-based and school-based programs that respondents' children attended were mostly segregated; however, a substantial minority were integrated.

While 95% of our sample reported that the program their child attended for the most hours cared for "other children with disabilities," 24% also reported that the program served "other children without disabilities."

14. Respondents whose children attended center-based or school-based programs usually reported attendance of 20 hours a week or less. Respondents from our suburban sample reported children were attending programs for more hours than did respondents from our urban or rural samples.

Of those whose children attended center-based and school-based programs, just 32% of respondents reported attendance of more than 20 hours per week, with 25% reporting 10 hours or less, and 43% reporting 11 to 20 hours a week.

However, of the respondents in the suburban Dutchess County sample whose children attended centers or schools, 42% attended for more than 20 hours a week. This contrasted to only 23% in the rural area and 32% in the upstate urban area. (In Brooklyn, where the sample was gathered through an agency providing home-based services, none of the respondents had children in any programs over 20 hours a week.)

15. Respondents whose children attended center-based or school-based programs were generally very satisfied with these programs.

Asked to check off "aspects of this program, if any, you wish to see improved," 44% of respondents checked none of them. The items checked most frequently were convenience of hours (13%) and facilities (13%); next were specialized services caregiver provides (9%), and caregiver training (7%). Cost was checked by only 2%--apparently because respondents were receiving nearly all the programs at no charge to themselves. Dutchess County respondents--whose children attended programs for more hours--were more likely than respondents in other areas to identify aspects of care that they would like to see improved.

A mother of a three year old from Clinton County with speech delay attending a segregated program wrote that "I was very satisfied, the results were amazing. My son was speaking in sentences in a very short time."

An Erie County parent of a two year old child with Down Syndrome and a heart defect wrote, "I've seen the largest jump in developmental growth in my son since putting him into an integrated preschool setting--totally integrated. If state budget will still allow...we will be beginning itinerant therapies on site to allow him to be in one program instead of two. I think this is ideal for him and kids like him."

The mother of a three year old from Erie County with cerebral palsy wrote of a UCPA program, "very satisfied. It is an excellent program and we see improvements continuously because of the knowledge of the people who care for him. This would not have happened in day care."

The foster mother of a four year old from Rensselaer County who had Down Syndrome and speech delay, wrote, "Very satisfied--the director and program staff were very willing to accept our child and we have worked closely to achieve integration. Sure, we had our share of parents 'not wanting my child with a retarded youngster,' but the supportive staff helped all of us to work through these issues."

The mother of a five year old from Johnstown (Fulton County) who attended a UCPA prekindergarten program in conjunction with the public school wrote that, "the present pre-K classes provide much of what my daughter needs to progress to a normal life. We hope she will be mainstreamed into regular public school in September 1991."

A Chatauqua County parent of a five year old with cerebral palsy says that, "at age three, the teacher at the nursery school was concerned about accepting my child because she was not walking independently and might fall. She tried to refer me to 'special' schools, however she consented to try having my child in the classroom. It has worked out well."

A parent of seven children, whose four year old child with hearing impairment and speech delay was dually enrolled in Buffalo Hearing and Speech as well as Head Start wrote, "Speech school helps him to speak, which he needs. Head Start has excellent lunches and breakfasts, school trips and reads to them."

A parent from Jamestown (Chatauqua County) was so impressed with her child's experience in an integrated program that she is entering the field herself: "The day care was very patient with T. They treated her as if she had no disability. They talked and didn't get angry when she did something wrong...Ever since I found out about my daughter's disability, I'm starting college to become a day care provider for children with disabilities and without--to help other people with children."

16. Families with higher incomes were more likely to report children attending programs outside the home than families with lower incomes. Children from families with higher incomes were also more likely to be in some kind of care other than (or in addition to) a special education program.

Respondents with annual household income below $25,000 reported only 48% of their children attending centers or schools outside the home, while 76% of respondents with incomes from $25,000 and up reported their children attending such programs. Some--but not all--of this difference is accounted for by the higher incidence of poverty among our sample in the rural area, where geographical realities make it more common for young children to be seen at home.

While 50% of respondents with incomes above $50,000 reported their children received care somewhere other than a special education/early intervention program, just 29% to 33% of respondents in lower income groups reported such practices.

"Until lately," wrote a low-income, single parent of a five year old with histidemia and multiple disabilities from Niagara Falls, "I was not aware of the services available to disabled children and their families..."

17. Employed mothers were more likely to report their children attending programs (centers or schools) outside the home than non-employed mothers.

We found that 71% of the employed respondents (93% mothers) in our quantitative sample reported their children attending center-based or school-based programs, while 59% of the non-employed respondents reported their children attending programs.

A clinician in New York City told us that, "Of course, if you know the mother is trying to go out and work, you'll try your best to see that the evaluation calls for more hours of program--maybe the child could get by with two or three days a week but you write it up so it will be five. These parents are desperate; they have no alternatives!"

18. "Care in someone else's home" was about evenly divided between relatives, licensed family day care, and others. Half of the respondents who used this type of care used it for more than one child and most of the homes cared for children other than the respondent's children and the caregiver's children. Most of the other children present were non-disabled.

We found that 27% of our respondents using "care in someone else's home" were using a licensed caregiver. Slightly less, 21%, were using a relative. It appeared that others were using friends and unlicensed caregivers.

While 53% of our respondents had only one child receiving care in someone else's home, 33% had two children and 13% had three or more children receiving care. Our respondents reported that 69% of these caregivers included "children from more than one family (not counting his/her own)."

While 20% of respondents who used this type of care indicated that there were other children present who also had special needs, 88% reported that there were other children without special needs.

19. Employed mothers were much more likely to report using care in someone else's home than those who were not employed.

While 40% of our employed respondents (who were 93% mothers) reported that they used "care in someone else's home," just 16% of our non-employed respondents used "care in someone else's home."

20. Respondents who used "care in someone else's home" usually reported using it for 20 hours a week or less.

Only 31% of our respondents who used care in someone else's home used it for more than 20 hours a week, while 31% used it for 10 hours or less and 38% used it for 11 to 20 hours a week.

21. Care in licensed family day care was as likely to be of a child with a severe level of disability as to be of a child with mild or moderate levels of disability.

The children of respondents in our sample using licensed family day care were equally distributed among the three levels of severity.

22. Respondents who used "care in someone else's home" were generally very satisfied with the care their children received.

Asked to check off "aspects of this care, if any, you wish to see improved," most respondents neither checked any of 10 items given nor opted to write anything in the space for other. The item checked most frequently was cost (16%); next was facilities (13%). All other items were checked by fewer than 7% of respondents. No respondents (0%) were concerned about "how caregiver relates to child," or "caregiver training."

A mother of a three year old with cerebral palsy and visual impairment from Mayfield reported that she only used an integrated family day care 2 hours a week for occasional respite, but was "satisfied because she was left exclusively with family who knew her specific needs."

A mother of a three year old from Erie County who used about 9 hours of family day care per week reported that if her daughter did not have special needs, she would have her only in "home care...I am satisfied with the care. They are very good when B. [has] seizures."

A mother of a one year old with Down Syndrome from a rural community in Orleans County stated that she was "somewhat satisfied" with the family day care her child attends for 30 hours a week "because of opportunity for integration. However, unsatisfied because of cost (I am a college student) and general lack of choice in this area."

23. Respondents' children attended most out-of-home settings (both center-based and home-based) year-round, with smaller numbers attending school-year only.

Of respondents whose children attended centers or schools, 71% attended year-round. Of those who used care in someone else's home, 69% attended year-round. All of the other respondents whose children attended centers or schools (29%) attended school-year only. However, the use of care in other people's homes broke down into a variety of categories, including 9% school-year only, 3% summer only and the rest sporadic or occasional.

24. The cost of attendance at centers or schools was usually not paid for by the respondents. In contrast, respondents usually--but not always--paid for care in other people's homes themselves.

Of respondents whose children attended center or school programs, 84% indicated that all or part of the cost was paid by a public or private agency. (It appears that it was nearly always the entire cost and the costs were paid by the federal government, local school districts, the state and/or the county.)

Out of the respondents who used care in someone else's home, just 13% indicated that a public or private agency "paid for some or all of the cost."

Martha Brink, parent coordinator for the Regional Planning Group in Essex and Franklin Counties, told us that, "The way things are now, you have to pay for day care yourself. You don't have to pay for the preschool [special education] programs. It's obvious which ones people are going to choose."

25. Nearly half of respondents would like to have additional hours of child care or respite care. Interest in additional hours of child care was greater among the following: those who reported that child care arrangements caused job-related difficulties; those not currently using child care; lower income respondents; rural respondents. Among those who reported that lack of child care kept them from being employed, interest was greatest of all.

We found that 38% of respondents would like some additional hours of child care and 22% would like some additional hours of respite care. The proportion that wanted either one or the other was 49%. Of those who wanted additional hours of either type of care, most would like ten hours a week or less. The same numbers held for respondents whose children had different levels of severity of disability.
Among the respondents who reported job-related difficulties in connection with care arrangements for a child with disabilities, 56% would like additional hours of child care or respite care. Of those not currently using child care, nearly half (47%) would like to have some additional hours. While 45% of respondents with annual household incomes under $25,000 wanted additional hours of care, the figure was only 29% for those above $25,000. Among our rural sample, 52% of respondents would like more child care.

The largest proportion wanting additional hours of care (69%) was found among respondents who reported that lack of child care had kept them from being employed.

A single mother from Bedford Stuyvesant explained that, "when you have a handicapped child and you need to go out and work, sometimes you're scared to leave the child with a sitter. I know I was scared. When I asked a social worker about getting some kind of care, I was told that I might be able to get a couple hours of care to go shopping once a week or something. That is dumb! They really need to have programs to take care of children and let parents go back to school or get a job."

A mother living on the St. Regis Mohawk Reservation in Franklin County has had to leave jobs when the babysitters she uses for her two year old child with special needs find other jobs. "The only care available is in private homes."

26. Respondents were remarkably unified in calling for the state to provide specialized services at regular early childhood locations. Next, they wanted help with paying for child care.

Respondents were given a list of 9 "possible ways in which the state might assist families with children with disabilities get child care," and were asked to indicate their first, second, and third choices (or to add selections, under other). Fully 45% of respondents selected the same item

as their first choice: provide specialized services at a regular early childhood/child care location. The only other item which received more than 10% of the first choice selections was increase assistance with paying child care fees (21%).

Lumping together the respondents who marked any given item as either a first, a second or a third choice, we find that 64% of respondents wanted the state to help with the specialized services at regular settings, 49% to assist with fees, followed by provide parent support/education (42%), provide support or training for child care providers (34%), and improve child care resource/referral system (30%).

By geographical area, the respondents that most wanted the state to provide specialized services at regular settings were the suburban (73%) and the upstate urban (75%) samples, as contrasted to the rural area (52%) and the downstate urban area (54%). It was the latter two areas that most wanted help with paying fees for child care: rural sample (66%) and Brooklyn sample (71%) as contrasted to the suburban sample (35%) and the upstate urban sample (20%).

Not surprisingly, respondents who had looked for care in a generic setting during the past year wanted the state to help with specialized services at regular settings (73%), as did an even higher 77% of respondents whose children have ever been refused care on account of disabilities. But a very strong 59% of respondents who had not looked for care in generic settings and 62% of those whose children have never been refused also wanted this kind of action from the state.

The interest in improving the resource-and-referral system came most strongly from those whose children were currently receiving integrated services, with 38% choosing this as one of their three selections, as contrasted to only 26% of those whose children are in segregated programs.

A Buffalo parent whose child, diagnosed with severe speech delay, attended a segregated program, seemed to speak for many others who would like the state to move towards more specialized support for integrated models: "I've always questioned why segregate the child. I'm told [it's] for his benefit, to avoid frustrating him. I don't agree...I want my child in a normal environment. I feel his speech could be improved if he sees other children speaking...I don't know of any integrated child care so I assume it is the law because the state will only pay for special education preschool programs."

A mother of a three year old from Depew (Erie County) commented, "I only wish I could get child care and speech therapy in the same place." She takes her child two days a week to a hospital "for speech and 3 days in preschool," in addition to some other hours in family day care.

A comment from a mother from a two-parent, low-income household linked the issues of regular settings and fees. "I have two children. Only one has delays in development," she wrote. "It would be nice for both of them if they could go to the same school...The cost of appropriate child care exceeds the salary that I could make...I would be happy to volunteer my time to take care of the extra children."

The issue of fees was also highlighted by a parent from rural Orleans County, who wrote, "if my child is two years old and still cannot walk or feed himself, I will still be charged higher infant rates."

Another aspect of fees was highlighted by a qualitative survey respondent from Greene County, the mother of a four year old with speech impairment: "Have places offer part-time classes; not everyone can afford $60-$75 a week on day care or nursery school for full time. No one offers part time around here."

The issue of support and training for providers was highlighted by a qualitative survey respondent from Schenectady County, who recommended, "Training for staff at day care regarding special needs children must be offered on a regular ongoing basis. Fear of the unknown is the biggest reason for lack of integrated day care."

CONCLUDING THOUGHTS

The two forms of data-gathering produced strikingly convergent results. Some clear and strong themes emerged from the quantitative sample, and these themes were amplified and explained in greater detail by those who filled out the qualitative surveys.

One of the most important findings is the lower participation rate by mothers of children with disabilities in the paid labor force. Our quantitative sample found only 35% of the respondents working outside the home, compared to 54% nationally of the mothers of children under six. If we had excluded the Brooklyn portion of our sample (because we were not able to draw a random sample there) the percentage of those employed would only have gone up a few points, to 38%. It seems clear that in respect to paid employment, raising a young child with a disability has a powerful impact on a very large number of mothers. It would be fair to say that at least one out of six have made major sacrifices in this respect, while a larger number (half or more) have made adjustments and compromises.

It would be an error, however, to infer that all of these mothers (and other guardians) who have made sacrifices, adjustments and compromises feel aggrieved and speak in unison when it comes to asking the state to help them. Rather, two quite distinctive choruses emerged from the qualitative survey respondents--at least upon reading between the lines. One chorus identified the compromises and sacrifices they had made while declaring that devotion to their children with disabilities was paramount and that public policy should continue to support the children in whatever way was considered best for them, even at the cost of further parental sacrifice. The other chorus also identified the compromises and sacrifices they had made, but coupled this with a plea for policies sensitive to their needs and aspirations as well as those of their children.

Interestingly, these two choruses seemed to sing in harmony on one area of public policy: the wish for special services to be provided at regular child care and early childhood settings. Apparently, many mothers in the first "chorus" have come to believe that their children have a better chance to improve in speech, social interaction, self-help skills and other areas if they spend time around non-disabled peers without losing out on therapies and other special support. At the same time, mothers from the other "chorus" recognize that access to regular settings with special services may allow them to solve their child care problems without setting back their children's development.

Many of these mothers' lives truly have been "turned upside down" by the responsibilities of rearing children with disabilities. Public policy makers need to recognize that reality, but also respect the fact that parents have not emerged from that experience as a monolithic group to be lumped together as one. Fortunately, there is at least one public policy path that will find a receptive audience, even among parents with differing perspectives and priorities. It is hoped that in the wake of this report, New York and other states will move to make available special services and supports in regular child care and early childhood settings so that children with disabilities can attend them alongside children from other families in their communities.